Making service user and carer feedback count: a student perspective

by Emma Farrow and Anne Day, final year BA Social Work students

As final year social work students we are in a unique position to comment on the value of service user and carer input in our learning on the degree course, how this has stayed with us through our placements and most importantly how this learning will forever impact on our professional practice. As students we have benefitted from having members of the Partnership Initiative speak to us about their lives and deliver talks about their presence in social work as expert by experience.

During our first placements in September to December 2014, we were required to obtain feedback from individuals that we had worked with, this task had two objectives one of which was to complete our portfolio and the other was to show the reception we had received having worked alongside services users, some of us, for the first time. Naturally, as students being assessed, we all chose to include the feedback that showed us in a shining light, the best thing to happen to social work since...well you understand.

We were then invited to attend a meeting in the summer of 2015 where collecting service user feedback was a hot topic. Simply, service user feedback was not serving its correct purpose. It was not showing any progression in student learning and was definitely not adhering to social work values in the fact that previous methods of collecting feedback did not consider issues of power and control.

Handing someone a questionnaire to complete whilst in the room keenly grinning at them whilst the individual tentatively ticked boxes was not demonstrating anything, except the students’ ability to make a table on a Word document.

As students we felt very strongly that things must change! And we support wholeheartedly a move from not just fulfilling the obligation to
the portfolio but to the people we are working for. So this year gathering feedback from clients will not be just a tick box exercise it will be a well thought through process that requires input from our Practice Educators and creativity from us as students.

It is only fair that the individuals that allow us into their lives are then given a fair opportunity to comment on our practice, warts and all, as this is the only way students can truly improve.

PI Member profile: Craig Potter

I'm Craig Potter. I live in Whitstable with my wife & three daughters. Since graduating from Canterbury Christ Church University with a 2.1 in Business and Applied Social Science, I've worked for the Centre for Independent Living Kent, Canterbury City Council, as a consultant, responsible for their first draft Disability Equality Scheme. I was an access consultant and auditor with a private company before become a Regional Manager and team leader for tenant engagement, then regulatory projects manager for AmicusHorizon, a social housing provider.

I've spent the past decade as a sessional lecturer to Occupational Therapy and then Social Work students at Christ Church. I'm a qualified HR specialist and currently an independent Disability Advisor to the Canterbury Branch of the Universities and Colleges Union. I'm a lifelong wheelchair user and Doctor Who fan.

PI Member profile: Hannah Tutt

I'm Hannah and I'm very pleased to have joined the PI steering group and hope my experiences will give you an insight into what it’s like to be dependent on the local authority and the government to provide support to a disabled person, and that any knowledge I may have will of benefit to you within your studies and beyond.

I was born with quadriplegic Cerebral Palsy, this has just affected me physically, and consequently I am a full-time powered-wheelchair user and fully dependent on others in supporting me 24/7. Nevertheless I have never let my disability get in the way of living life to the full and having an active role in the society.

I have achieved a lot, I live independently, I am an employer of my own team of Personal Assistants covering 24/7 and I do a lot of voluntary work. The main work I do is at the Centre for Independent Living Kent (CiLK) where I am Chairperson. CiLK is controlled and managed by disabled people to provide information and advice to disabled people across Kent and Medway on a whole range of disability-related issues and resources. We are a registered charity and we also do disability equality training and we have just set up a new disability awareness programme called “Disability’s ok” to go into schools to make disability less of a taboo subject for children. We are aiming this at primary schools firstly and if it’s a success hoping to do a similar programme in
secondary schools in the future. We are a growing organization and we are now able to offer more services that in the past.

I am currently having to undergo the PIP (Personal Independence Payment) assessment which is transferring over from DLA (Disability Living Allowance) benefit. I have been on DLA since I was 3 years old and was granted an “indefinite award” from DLA but with the new government legislation changes regarding benefits and the introduction of PIP it’s not as simple or as smooth as it should be to transfer from one to another and all disabled people have got to claim PIP when their DLA is being transferred.

I had my letter to say my DLA was ending and if I wanted to claim PIP to ring the claim number before the deadline date given. This was around Christmas time so wasn’t the most convenient time to start the application process. I made the phone call and they asked me the basic questions about my disability and said the application form would be sent out to me.

The application form came just before Christmas, on the 23rd December and the deadline to send it back by was the 12th January so really quite a tight window to fill it in by. The form was 36 pages long and they wanted quite a bit of information about what you can and what you can’t do, for each question, and in my eyes some of the questions were a bit repetitive. I could imagine that if you were suffering from depression over your disability that this form could make you even worse! Seeing the little you can do written down in ‘black and white’ doesn’t really do much to make you feel good about yourself! I returned the form by the deadline and awaited their response, within a couple of weeks I had a phone call on a Friday to ask if they could come out to do a face to face visit on the Monday, which I agreed to as I wanted to get it over and done with.

On the Monday morning a lady duly arrived from Atos, she wanted two forms of ID from me and then proceeded with her assessment which included all the questions from the form I had previously completed and also at the end she requested me to sit and face her and follow her actions, something similar to ‘Simon Says’! I felt humiliated and demeaned as she didn’t take what I had verbally told her as being the truth, and had to make me go through many actions to prove herself that what I said on the form was correct! I felt I had to go ahead with her requests because she was the one reporting back to the decision maker who held the ‘purse strings’! I asked her if she was medically trained and she informed me that she was a trained paramedic.

She told me that a decision would be made in approximately 6-8 weeks, so I sit here holding my breath for the final decision.

The whole procedure is not a good experience for anyone and I hope at the end of the day it will all prove to be worthwhile and me benefits will remain the same, it is a worrying time for all disabled people so I am not alone, and it seems to me that disabled people have to spend their lives fighting for the things they need to live.
Staff Profile: Mandy Twyman

Hello, my name is Mandy Twyman. I have been working with many of you for over 5 years now having first started at the University over 20 years ago and have seen many changes along the way. My general role is to support the finance team with the processing of purchase orders and invoices and being the point of contact when any problems arise.

I came over to Medway on 9th February, certainly should have happened much sooner, I met several PI members, which was wonderful meeting so many and I can put faces to names that I’ve spoken with over the years and you can do the same. I can now appreciate individual’s need, work with your to make the processes and getting paid a much improved system.

I plan on making this a regular occurrence so that I can get to see more PI’s and address any possible issues that may crop up in between times. I wanted people to see the human side of me, especially as working in finance it can portray people as officious and difficult and I hope I waylaid any preconceived idea of how I work. I am here to assist you in any way that I can.

I look forward to continuing to working with everyone and meeting those I missed earlier on this year.

A mental health manifesto for BME service users & carers

by Raza Griffiths, PI member

As well as my university based work at Kent and Canterbury Christ Church Universities, I work part time as the Lead for the Kindred Minds mental health manifesto project. Kindred Minds is led by mental health service users and aims to enhance the well-being and promote the rights of people from black and minority ethnic communities affected by mental distress in Southwark and neighbouring boroughs in London.

Over the next year and a half I am undertaking consultations with minority ethnic communities to inform the writing of a mental health service user manifesto with funding from Trust for London. The manifesto will highlight the aspirations of black and minority ethnic mental health service users and what changes we want to see to the policies and practice which affect our mental health and wellbeing. Wherever possible we will also be highlighting how BME service users can also be part of the solution, such as through the development of peer support.

The manifesto has a social change and rights based agenda and sits well with social work perspectives which see mental health in the context of broader social issues and power dynamics. So as well as addressing the need for urgent change within the mental health system on issues such as over use of compulsory treatment and detention and lack of access to talking therapies for black
– particularly Black African and African Caribbean communities - the manifesto will focus holistically on community development, poverty alleviation, racism and discrimination, peer support, benefits, housing, education and policing.

In writing the manifesto we want to link up scattered initiatives and projects, and use the manifesto to create a rallying point around which BME communities can unite and then take united action to influence the policies and practices affecting our mental health and wellbeing. Now is a vital time to be doing this work because of the devastating effect of continued cuts to benefits and services, which are disproportionately affecting poorer people in inner city areas, where BME communities are concentrated. This is on top of the ongoing need to challenge institutionalised racism in many areas of life.

For further information please contact Raza Griffiths, Kindred Minds Manifesto Lead at: razagriffiths@gmail.com

**Bournemouth University Conference on service user & carer involvement**

*by Mike Thomas*

On 28th October 2015, Sarah Brown and I represented the University of Kent at a conference on user and carer involvement in higher education programmes. Social Work was well represented at the conference alongside other disciplines such as physiotherapy, occupational therapy and nursing. The focus of the day was on making and developing contacts between the 28 universities from across England and Wales represented on the day, as well as highlighting potential areas of good practice.

The conference also considered some of the challenges of integrating user and carer perspectives into degree programmes; some of the priorities identified by participants including making sure that user and carer involvement was meaningful rather than tokenistic, getting senior managers within universities to take user and carer input seriously, and working to put users and carers in the driving seat within existing mechanisms for involvement, rather than relying on academics to take the lead.

There was a clear consensus on the value that carer and service user involvement adds to degree programmes in a range of subject areas. Students at the conference told us that user and Carer perspectives provided a reality check on course content and theories, and that feedback from users and carers was particularly helpful in guiding their development as individual practitioners. User and carer representatives made clear the sense of personal satisfaction and empowerment they got from being involved in education, but offered a number of important pointers for academics. These included the need for adequate notice of forthcoming events so that they could plan their involvement without feeling rushed or pressured. Academics were asked to bear in mind the need for effective and supportive preparation, as service users and carers might not always feel confident, particularly when trying out a new activity. Debriefing was also important, to give a chance for service users and carers to give feedback to academics after a lecture or workshop. These are areas
we have been discussing within the Partnership Initiative group at Kent over the past year. There were also lessons for universities, who could do more to share information between themselves on user involvement: this conference was intended as making a contribution to this longer-term process.

Further information on user and carer involvement is available via the following links:

Lived Experience Network (LEN) http://www.alps-cetl.ac.uk/len.html

Shaping our lives network of service users and disabled people: http://www.shapingourlives.org.uk

Conference participants 'sculpting' their views of user and carer involvement. Keen-eyed readers will spot Sarah Brown and Mike Thomas taking part in this activity. Image ©Bournemouth University.
Editorial: Is the future red?

by Joanna Whisker

As reported in the Gravesend Messenger by Nick Lillitos (13.1.16) a £126 million contract to run community hospitals covering Dartford, Gravesham and Swanley for 7 years from 1st April 2016 has been awarded to Virgin Care, with the possibility of extending the contract for a further 3 years.

The contract includes Sittingbourne Memorial Hospital and Sheppey Hospital but in all areas the contract to Virgin Care includes adult health community services, which will be free at the point of delivery, but does not include the buildings. Current providers Kent Community Health NHS Foundation Trust have expressed their disappointment particularly as they scored slightly higher than Virgin Care for quality but not on price, even though they consider themselves to have one of the lowest running costs of any NHS community provider in the country.

Will Virgin Care be able to provide and develop a service that meets the needs of an increasingly diverse population with complex needs on a decreased budget?

What is particularly interesting is that although the bidding process started in 2014, I am unaware of consultation with, or information given, to users of the services and no evidence of an impact assessment despite current political promises of transparency. No doubt it is left to individuals to do their own research, as is evidenced by the fact that community nurses in my area still have little official information about what their future will be under Virgin Care, apart from being reassured there will be reductions in the levels of bureaucracy. Simple decisions such as which uniform to wear have yet to be made. They have resorted to checking online news reports, and are already fed up with being asked if they will be wearing red stilettos and flashing red lipped, white, bright smiles!

The Virgin Care website (virgincare.co.uk) explains that all community services are localised but have a common approach based on improving your experience, listening to you, providing care in the most appropriate place, and a being safe and consistent.

Add to this their values, described as the 'moral compass and core to their DNA' are described as being caring, outstanding, innovative, outcome-driven, fun, and 'wow' (!)

Who will profit from this ground-breaking change to adult health care services? Virgin Care is proud of its ten year contribution but with the start date already being delayed, is it now time to ask: is community care about to fly high above the bureaucratic mountain, or will it crash under the weight of the 'burden of care?